TLC-Asthma: An Integrated Information System for Patient-centered Monitoring, Case Management, and Point-of-Care Decision Support

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ABSTRACT

A great deal of successful work has been done in the area of EMR development, implementation, and evaluation. Less work has been done in the area of automated systems for patients. Efforts to link data at multiple levels – the patient, the case manager, and the clinician have been rudimentary to-date.

In this paper we present a model information system that integrates patient health information across multiple domains to support the monitoring and care of children with persistent asthma. The system has been developed for use in a multi-specialty group practice and includes three primary components: 1) a patient-centered telephone-linked communication system; 2) a web-based alert reporting and nurse case-management system; and 3) EMR-based provider communication to support clinical decision making at the point-of-care.

The system offers a model for a new level of connectivity for health information that supports customized monitoring, IT-enabled nurse case-managers, and the delivery of longitudinal data to clinicians to support the care of children with persistent asthma.

Systems like the one described are well-suited, perhaps essential, technologies for the care of children and adults with chronic conditions such as asthma.

INTRODUCTION

The application of information technology to medical care involving patients as users has traditionally relied on stand-alone desktop computers in patient homes.[1,2] More recently, advances in telecommunications technology have made it possible to link patients in their homes to computer networks via computer, telephone, and other devices[3] – creating new opportunities for the application of information science to support the ambulatory care of patients and consumers. These new technologies are especially well-suited for the monitoring and care of chronic conditions such as asthma.

Asthma is the most common chronic disease of childhood and its prevalence has been increasing in the U.S.[4] Despite the success of modern pharmacotherapy, asthma care in the U.S. is often sub-optimal. Anti-inflammatory drugs have been under-prescribed by clinicians and under-used by patients.[5] Patient self-monitoring of peak expiratory flow rate (PEFR) using a peak flow meter (PFM) as recommended by the NAEP and others is frequently not done. In addition, asthma severity is often under-diagnosed due to a lack of information regarding symptoms of persistent disease outside the clinical encounter.

Efforts to improve the quality of asthma care have focused primarily on the areas of patient education and case management. However, these approaches are labor intensive and costly, and thus are practical only for the most severe patients with asthma. Furthermore, both approaches are often limited by the lack of information regarding asthma symptoms at home.

Computer-based telecommunication technology offers great potential as a cost-effective tool for 1) monitoring asthma symptoms and patient knowledge outside the clinical encounter; 2) providing enhanced education and case management when problems are identified; and 3) EMR-based provider communication to support clinical decision making at the point-of-care.

In this paper, we describe an integrated information system developed to link patients, case managers, and their primary clinician in an effort to improve

the quality of asthma outcomes and care using: 1) a telephone linked patient communications system; 2) a Web-based alert reporting and nurse case management system; 3) transfer of patient reported information to primary care clinicians; and 4) use of EMR-based reporting for clinical decision making at the point-of-care. The system has been developed for use within a multi-specialty group practice in eastern-Massachusetts.

Our goals are to describe the design of the system, highlight some of the unique features and considerations of a computer-based telecommunication system for children, and offer a model for an integrated information system that combines patient-centered monitoring and education, Web-based case management, and EMR-based reporting and decision support (Figure 1).

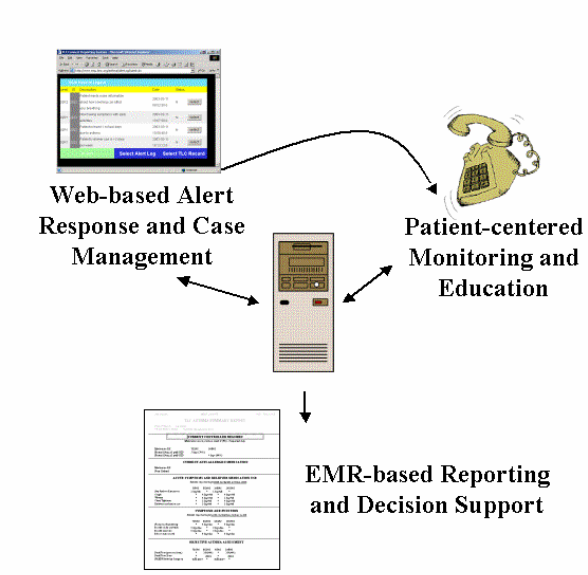


Figure 1. TLC Asthma System Architecture

PATIENT-CENTERED MONITORING AND EDUCATION

The TLC (Telephone-Linked Communications) system is a computer-based telecommunications system developed to be an at-home monitor, educator and counselor for patients with chronic health conditions.[6,7] TLC carries out totally automated telephone conversations with patients. During TLC telephone conversations, the system speaks to patients using computer-controlled digitized human speech. The patients, in turn, communicate with TLC by pressing the keys on their telephone keypad or by speaking into the telephone receiver. During TLC conversations, TLC asks the patients questions to monitor their health conditions; it also provides education and behavioral counseling for targeted health-related behaviors such as medication taking, diet and exercise. After each conversation, TLC stores the information the user has communicated in a database.

Either the patient or TLC may initiate a conversation. Should the patient fail to call when expected, TLC will call the patient. In addition to questioning the patient, TLC provides education and behavioral reinforcement, such as counseling on how to take medications at prescribed times. TLC conversations were designed to emulate telephone conversations between patients and health professionals. A typical conversation lasts between three and five minutes, depending on the number and complexity of the topics addressed and the user's responses.

The telephony system runs on a Windows NT computer using a D120x Intel/Dialogic board to interpret DTMF tones and play compressed voice files. The system was programmed in Visual Basic and Visual Voice platform. Automated faxing and reporting features are developed in Visual Basic and faxing is provided by FacSys Fax Server. Data is stored in an Oracle 9i database.

TLC-Asthma is designed for use by children between the ages of five and sixteen with mild-moderate persistent asthma and their parents. Educational materials and scripts have been prepared for four groups based on current grade in school (K-1, 2-3, 4-6, 7+) to provide material appropriate to the cognitive/developmental stages of children and the differing roles that parents play in disease management at these different ages. TLC-Asthma converses with both the patient (the child) and a responsible parent or guardian, in separate conversations. Both child and parent receive customized asthma education during TLC conversations. For example, in a particular TLC-Asthma conversation, education regarding environmental control is limited to a discussion of dust avoidance when addressed to the young child, but is deeper and broader when directed to the parent, including information on the life cycle requirements of dust mites (e.g., high humidity, skin scales, etc.) and information on how to obtain and use covering materials.

The content of TLC-Asthma conversations is based on the NAEP Guidelines for the Diagnosis and Management of Asthma[8] and educational material written for the NHLBI's Childhood Asthma

Management Project (CAMP), an on-going multi-center clinical trial of anti-inflammatory therapy. Content areas for monitoring and education have been developed and are addressed on multiple occasions during sequential cycles. The monitoring components include: severity-treatment mismatch, assessment of the use of a home peak-flow meter (PFM), symptom level, functional status, and knowledge and adherence to the prescribed medication regimen. The educational components include: 1) recognition of asthma symptoms, particularly those that might indicate an exacerbation; 2) potential triggers of asthma and steps that should be taken to mitigate them; 3) exacerbations and how to deal with them; 4) medication use; 5) pretreatment; and 6) appropriate use of the health care system including regular office visits and urgent care. TLC-Asthma educates by first assessing knowledge and then providing targeted education as required.

For all calls, the system inquires whether the child has had any changes in his asthma symptoms and if so, which symptoms changed and their frequency. If the child has had a change in symptoms, the conversation moves to a targeted inquiry of potential triggers of the worsening symptoms. For all calls, TLC-Asthma also inquires about functioning.

Finally, in each weekly conversation, TLC-Asthma asks several questions related to asthma knowledge. Each important piece of information is put in a form of a yes-no question. In response to the user's answer, the system provides constructive educational feedback to help the user learn. The educational material is presented in order of its relative importance (e.g., medication use and actions to take for exacerbations are covered first).

At the end of each TLC-Asthma conversation, the system summarizes the most important points (take home messages) for the child, gives positive reinforcement for the child's efforts in self-care, reassures the child about his/her health status, and reminds the child to call the next week.

Several age-appropriate sports and entertainment celebrities have volunteered to provide voice recordings to better engage children during the computer-based interviews.

A WEB-BASED NURSE ALERT REPORTING AND ASTHMA CASE MANAGEMENT TOOL

During TLC-Asthma interviews, the system monitors each conversation for potential clinical problems or issues and, when identified, generates a system alert. Alerts are grouped into one of two levels. The system is capable of generating alerts for a broad range of clinical problems. Level 1 alerts are generated for responses that require immediate attention. For example, when a child or parent reports significantly reduced peak flow monitor readings (less then 50% of predicted) and lack of response to reliever meds, a Level 1 alert is generated. The patient is told to seek medical care immediately. For all Level 1 alerts, a fax is immediately sent to a dedicated fax line and the TLC system then calls a 24-hour phone number to notify responsible clinical personnel. Level 2 alerts cover a wide range of items ranging from medication supply and compliance to knowledge of key asthma content. Level 2 alerts are sent to the TLC Alert Reporting and Documentation System to be reviewed by the TLC-Asthma nurse. Alerts are viewed in the TLC-Asthma Alert Log (Figure 2).

The TLC Alert Reporting system has been programmed in Java, and uses a replicated Web-accessible database. Nurses using the system are able to see all alerts from a given TLC-Asthma interview, group them, provide documentation of response, create and customize a summary note and flag the note for transfer to the patient's EMR. The nurse can also use the software to view the patient's "TLC-Record" which includes all responses to TLC-interviews, summaries of previous alerts and responses, and a view of the Summary Report described below.

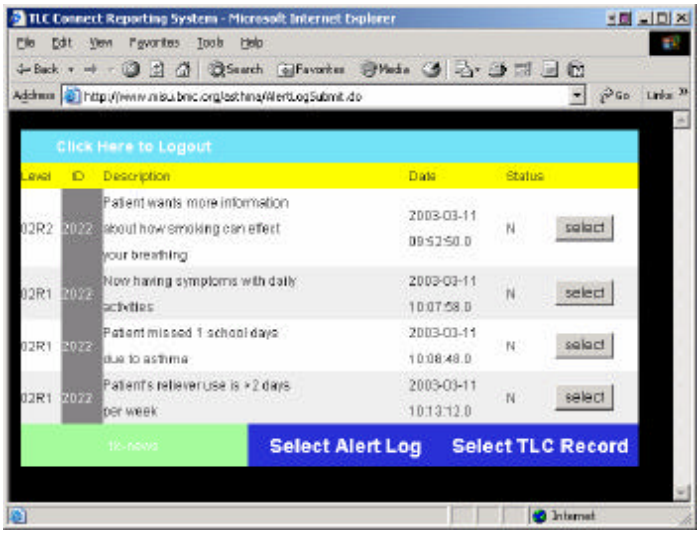


Figure 2. The TLC Alert Log

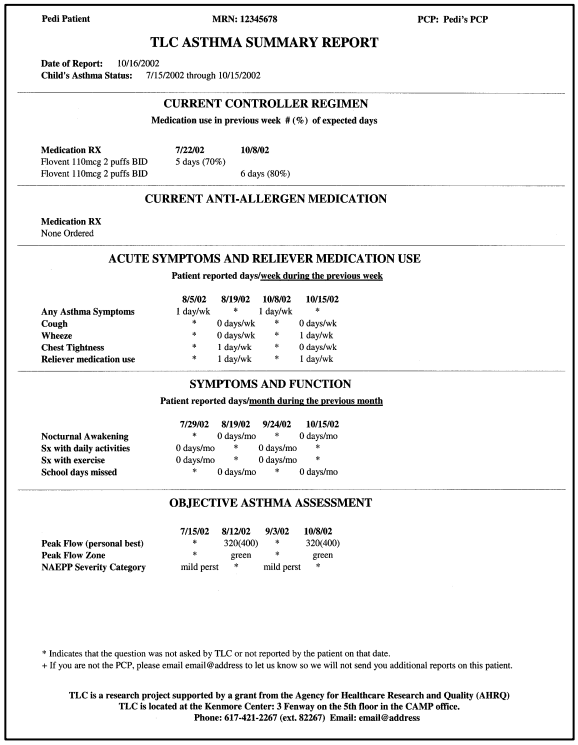
TLC-ASTHMA NURSE ROLE

The TLC-Asthma nurse is in essence, an IT enabled nurse case manager. The role of this nurse has been adapted from asthma case management systems already in existence.[9,10] There are, however, important differences in the role of TLC nurses. Nurse case managers traditionally educate the child and the parent about asthma and the role of both the child and the parent in the management of the child's asthma at home. They monitor the child's asthma by periodic telephone calls as well as through office visits.

The TLC-Asthma nurse provides basic asthma education at the beginning of the child and parent's participation in the study. Subsequent asthma education will take place during TLC conversations. The TLC-Asthma nurse does not have the responsibility for making regular telephone and office contacts with the child and/or parent in order to monitor the status of the child's asthma. This function is taken over by the TLC system. The presence of IT support, however, allows much closer monitoring of a child's asthma and the early detection of items in need of attention. For example, the TLC-Asthma nurse will know that a patient has no controller medicine at home well before the next scheduled visit to a primary care clinician or periodic phone call. The TLC nurse is responsible for two responsibilities that are specific to the TLC system. First, the nurse will contact the child and/or parent if either does not use TLC on a regular basis. Second, the TLC-Asthma nurse will monitor the TLC-Asthma Alert Log and document alert responses .

INTEGRATING PATIENT-CENTERED INFORMATION, CASE MANAGEMENT, AND THE EMR

Primary care providers for each TLC-Asthma patient receive documentation of all alert responses by the TLC-Asthma nurse. These reports include detailed descriptions of each alert, followed by nursing documentation of case-management interventions performed. Reports are sent to each provider via the internal EMR (EpiCare,EPIC Software Systems, Inc.) messaging system. In addition, key data gathered during TLC-Asthma telephone interviews is transferred to the EMR nightly via secure file transfer. These data are used to build a "TLC Summary Report" (Figure 3). The purpose of this report is to support clinical decision making by the TLC-Asthma patient's primary clinician. The report contains an updated asthma medication list and longitudinal data related to acute symptom frequency, reliever medication use, long-term symptoms and functioning, and objective asthma assessment measures. This report is updated nightly and available via the EMR at the time care is delivered by the primary care clinician. Clinicians are encouraged to review Summary Reports via in-service training, and prompts embedded in the text of every alert response note.



Pedi Patient **MRN: 12345678** **PCP: Pedi's PCP**

TLC ASTHMA SUMMARY REPORT

Date of Report: 10/16/2002
Child's Asthma Status: 7/15/2002 through 10/15/2002

CURRENT CONTROLLER REGIMEN

Medication use in previous week # (%) of expected days

Medication RX	7/22/02	10/8/02
Flovent 110mcg 2 puffs BID	5 days (70%)	
Flovent 110mcg 2 puffs BID		6 days (80%)

CURRENT ANTI-ALLERGEN MEDICATION

Medication RX
None Ordered

ACUTE SYMPTOMS AND RELIEVER MEDICATION USE

Patient reported days/week during the previous week

	8/5/02	8/19/02	10/8/02	10/15/02
Any Asthma Symptoms	1 day/wk	*	1 day/wk	*
Cough	*	0 days/wk	*	0 days/wk
Wheeze	*	0 days/wk	*	1 day/wk
Chest Tightness	*	1 day/wk	*	0 days/wk
Reliever medication use	*	1 day/wk	*	1 day/wk

SYMPTOMS AND FUNCTION

Patient reported days/month during the previous month

	7/29/02	8/19/02	9/24/02	10/15/02
Nocturnal Awakening	*	0 days/mo	*	0 days/mo
Sx with daily activities	0 days/mo	*	0 days/mo	*
Sx with exercise	0 days/mo	*	0 days/mo	*
School days missed	*	0 days/mo	*	0 days/mo

OBJECTIVE ASTHMA ASSESSMENT

	7/15/02	8/12/02	9/3/02	10/8/02
Peak Flow (personal best)	*	320(400)	*	320(400)
Peak Flow Zone	*	green	*	green
NAEPP Severity Category	mild perst	*	mild perst	*

* Indicates that the question was not asked by TLC or not reported by the patient on that date.
+ If you are not the PCP, please email email@address to let us know so we will not send you additional reports on this patient.

TLC is a research project supported by a grant from the Agency for Healthcare Research and Quality (AHRQ)
TLC is located at the Kenmore Center: 3 Fenway on the 5th floor in the CAMP office.
Phone: 617-421-2267 (ext. 82267) Email: email@address

Figure 3. Sample TLC-Asthma Summary Report

CONCLUSIONS

A great deal of successful work has been done in the area of EMR development, implementation, and evaluation. Less work has been done in the area of automated systems for monitoring patients with chronic conditions and alert responsible clinicians when problems are detected. Efforts to link data at multiple levels – the patient, the case manager, and the clinician have been rudimentary to-date.

There is a tremendous need to provide effective, low-cost education and monitoring for the large numbers of children with persistent asthma who do not have severe disease, but who are persistently symptomatic. Equally important is the need for tools to more effectively support nurse case managers in their efforts to identify patients in need of their services.

The TLC-Asthma system offers a model for a new level of connectivity for health information and a new level of interactivity for patients. The system supports highly customized delivery of health information to monitor and support the needs of children at different developmental stages. The system is also closely linked to the case managers who, with computer-assistance, can better prioritize and customize care for the needs of individual children. Finally, the system is capable of monitoring multiple factors at a frequency that could not be performed in most settings.

The TLC-Asthma system is currently being evaluated in a randomized clinical trial of 300 children with persistent asthma. A cost-effectiveness analysis will be conducted at the completion of the study. If found to be effective, and affordable, systems like the one described in this paper will be well-suited, perhaps essential, technologies for the care of children and adults with chronic conditions such as asthma.

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